

# **A I D S TREATMENT N E W S**

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Citizen-action campaigns (like getting people to call Congress or their state representatives to support Medicaid, ADAP, or other program for access to medical care) could get much more response if they were made accessible to the millions of people who are already supportive but not already involved. We suggest several ways to make action alerts and other citizen organizing work better.

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# AIDS Treatment News

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## Statement of Purpose:

*AIDS Treatment News* reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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## African-Americans and AIDS, Conference Feb. 24 and 25, New York.....

This national meeting brings leading experts and professionals together for lectures and networking. It offers continuing education credit for doctors and nurses, but is open to all.

## Antibiotic-Resistant Skin Infections Spreading among Gay Men, Also in Prisons

by John S. James

In the last few months doctors have seen a large increase in aggressive, antibiotic-resistant "staph" (*Staphylococcus aureus*) skin infections in gay men in some areas -- and a separate epidemic in certain prisons. Symptoms include boils or blisters; treatment can be difficult, and sometimes requires hospitalization. One HIV doctor in Los Angeles who used to see about one case a year is now seeing two a week. In the past this infection occurred mainly in hospitals.

Physicians should note a February 1, 2003 review in the *British Medical Journal* ("Old Drugs for New Bugs," *BMJ* 2003; volume 326, pages 235-236) on evidence for the value of older antimicrobials for resistant bacteria, including staph. It suggests using co-trimoxazole (Bactrim® or other brand names) as an alternative to vancomycin for resistant *S aureus* (also called MRSA). In one case co-trimoxazole was used successfully after a patient had failed the new and very expensive antibiotic linezolid (Zyvox®). The article is at:

<http://bmj.com:80/cgi/content/full/326/7383/235?maxtoshow=?eaf>

Below is a fact sheet published by the Los Angeles County Department of Human Services on how to avoid the infection (or avoid spreading it if you have it). Also, a fact sheet by the U.S. CDC, revised February 7, 2003, is at: <http://www.cdc.gov/ncidod/hip/aresist/mrsafaq.htm>

For a recent overview, see "Skin Infection Spreads Among Gay Men in L.A.," *Los Angeles Times*, January 27, 2003.

## **Fact Sheet Published by Los Angeles County Department of Human Services**

### **Antibiotic-resistant "Staph" Skin Infections**

Recently, doctors in Los Angeles have been seeing an increasing number of patients with skin infections caused by *Staphylococcus aureus* ("Staph") bacteria that are resistant to many antibiotics (drugs that kill bacteria). The Los Angeles County Department of Health Services is working with doctors and other healthcare providers to better understand why this is happening and how to prevent antibiotic (drug) resistant Staph infections from spreading.

What is a Staph infection? Staph is a bacteria commonly found on human skin. Sometimes it does not cause any problems; sometimes it causes minor infections, such as pimples or boils. Staph skin infections often begin with an injury to the skin. Staph enters the skin weakened by the injury and develops into an infection. Symptoms of a Staph infection include redness, warmth, swelling, tenderness of the skin, and boils or blisters.

How do Staph skin infections spread? The cleanest person can get a Staph infection. Staph can rub off the skin of an infected person onto the skin of another person during prolonged (skin to skin) contact between them. Or, the Staph can come off of the infected skin of a person onto commonly shared objects and surfaces, and get onto the skin of the person who uses it

next. Examples of commonly shared objects include personal hygiene objects (i.e. towels, soap, clothes), benches in saunas or hot tubs, and athletic equipment -- in other words, anything that could have touched the skin of a Staph infected person can carry the bacteria to the skin of another person.

How can I prevent myself from getting infected? Avoid prolonged skin to skin contact with anyone you suspect could have a Staph skin infection. Do not share personal items with other persons. Clean objects and surfaces that you share with other persons, such as athletic equipment, before you use it. Always wash your skin, clothes, and towels that might be carrying Staph.

What should I do if I think I have a Staph skin infection? If you suspect that you might have a Staph skin infection, consult your doctor or healthcare provider as soon as possible. Early treatment can help prevent the infection from getting worse. Be sure to follow each direction from your doctor or healthcare provider closely, even when you start to feel better. Weak or incomplete treatments of Staph infections lead to stronger, antibiotic-resistant bacteria.

If my health care provider has told me that I have an antibiotic-resistant Staph infection, what can I do to keep others from getting infected? You can prevent spreading an antibiotic-resistant Staph skin infection to those you live with or others by following these steps:

1. Keep the infected area covered with clean, dry bandages. Pus from infected wounds is very infectious.
2. Wash your hands frequently with soap and warm water, especially after changing your bandages or touching the infected skin.
3. Regularly clean your bathroom and

personal items. Wash linens and clothes that become soiled with hot water and bleach, when possible. Drying clothes in a hot dryer, rather than air-drying, also helps kill bacteria in clothes.

4. Tell any healthcare providers who treat you that you have an antibiotic-resistant Staph skin infection.

## **Retroviruses Conference, Feb. 10- 14; Sites to Watch for News**

The important 10th Conference on Retroviruses and Opportunistic Infections is February 10-14, 2003, in Boston. We will report some of the developments beginning in our next issue, #389.

Meanwhile, here are some Web sites that are likely to publish reports during or shortly after the meeting:

Official Retroviruses site,  
<http://www.retroconference.org/2003/>

The Body,  
<http://www.thebody.com/confs/retro2003/retro2003.html>

Clinical Care Options,  
<http://www.clinicaloptions.com> (new site from experienced team, plans extensive reviews, CME)

HIVandHepatitis.com,  
<http://www.hivandhepatitis.com>

Medscape,  
<http://www.medscape.com/viewprogram/2221>

HIV Insite,  
<http://hivinsite.ucsf.edu/InSite.jsp?page=md-02-04>

Aegis, <http://www.aegis.org>

National AIDS Treatment Activist Project, <http://www.natap.org>

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## **Building Grassroots Support for AIDS**

by John S. James

Today in the U.S. we are facing one of the worst climates ever for access to medical care and social services for AIDS and other needs. Government budget problems, combined with the dysfunctional financing of medical care, are threatening Medicaid, ADAP, and the long-standing agreement that most people with HIV in the U.S. can get treatment.

For years the AIDS community has done well in the media and in building public consensus on what needs to be done. But we have been much less effective in grassroots organizing -- in giving those who agree with us effective, satisfying actions for making their values and priorities known. Perhaps 1% of U.S. citizens who care about AIDS have *ever* let any of their political representatives know it. So Congress, the White House, and state and local governments seldom hear from their constituents back home. And that hurts everything that happens in AIDS.

After watching this happen for years, I have become convinced that we could do *much* better in mobilizing popular support, by slightly refocusing some of what we are already doing. AIDS organizations and activists already have the skills and resources required.

### **Improving Action Alerts**

As an example of what is needed, consider what must be changed to improve Internet action alerts so that they are truly accessible to everyone who cares, not only to experts or insiders.

A year ago, it was clear that we were being hurt in Washington because members of Congress were hearing

about AIDS (especially international issues) mainly from media and a few activists and professionals, but not from the voters in their districts. Since then important progress has been made. Now there are usually several action alerts and sign-on letters circulating at any one time. As a result, more people are contacting their representatives, and AIDS is treated more seriously in political circles.

These action alerts vary in quality and credibility. Some include errors that could easily be fixed, such as misspellings or obsolete information. More important are judgment issues that are harder to detect -- such as whether the alert is based on a thought-out, workable strategy, or only on somebody being upset one day and wanting to do something. And many alerts try to get people to act by hammering on how bad the problem is -- while those most likely to respond already know this, but need help with other obstacles.

The main problem is that unless people recognize a sponsoring organization or already know the issue very well, they have no way of knowing which action alerts they truly want to support. Therefore many alerts that may look accessible (because they correctly avoid jargon, abbreviations, or insider code meanings) are still effectively available only to those already involved. The general public, even those who completely agree on the issues, cannot use them intelligently.

Even very experienced activists have sometimes had to retract their endorsement of a campaign that turned out not to be what it seemed. How can we expect people to speak out on our issue if we do not negotiate the necessary credibility up front?

### **The Right Target Audience:**

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### **Those Who Care But Are Not Already Connected**

Action alerts should be credible, feasible, and rewarding to all who agree on the issue -- not just AIDS specialists. Here are some pointers:

- \* Any action request or other grassroots campaign should be designed for a target audience -- not for no one in particular.

For most alerts, we suggest addressing someone who already agrees on that issue, but may live miles away from the nearest AIDS organization or activist, and not personally know anyone involved. Imagine also that this person wants to bring the alert to his or her church group, civic or political club, or other social circle -- also non-experts. An action alert package must provide exactly what is needed to do so. Probably it will include a one-page explanation, plus a background document (or Web link, preferably to a page designed for that campaign) for anyone who wants more information.

People usually join causes not as individuals, but as members of social circles. Therefore, campaigns should facilitate group involvement, as well as helping individuals who want to act on their own.

- \* The action alert should be based on human values and not assume special knowledge of facts, or of their special significance. If it does include facts, these should be separated from the action item, so that people are not asked to sign someone else's research. Otherwise the alert will lose supporters unnecessarily, because many will feel that they do not have enough background to publicly endorse the factual statement. For example, everyone would agree that children should not die, but not everyone would

sign a statement saying that 610,000 children under 15 died of AIDS in 2002.

\* The way to make an action alert credible to the general public is to negotiate it in advance among different organizations and/or public figures, including some that are widely known and respected by the general public (such as Doctors Without Borders, which recently won a Nobel prize), or major churches, or popular celebrities. This may seem like a lot of work, but in fact it is already being done. For years AIDS organizations have developed sign-on letters, often endorsed by over a hundred well-known organizations, including both AIDS and non-AIDS health, political, religious, and other groups.

These sign-on letters do help. But unfortunately they waste most of their potential, because once they are released they are finished. They do not involve the public because they give people no chance to act. Usually the letter and signatures are delivered to some office, and perhaps a press release goes out. Then it is all forgotten, because there is no follow-through.

On the other hand, most action alerts do have the follow-through in public involvement -- but did not bother with consensus development. Generally they are sent out by one organization that is all but unknown outside the AIDS field. No wonder they cannot generate many letters, phone calls, or other actions requested, since only AIDS specialist can be confident that the action request is credible.

Imagine what could be done by combining consensus development with actions that any supporter could take. These action alerts could break out of AIDS circles and reach many more people.

\* One way to make it much easier for  
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someone to bring an action alert to his or her church group (for example) is to get a national office of that church to endorse it. Then all the members of the national group have an occasion to bring the matter up if they want to.

The way to get organizations to work together on a citizen-action campaign is to reach a meeting of the minds first. This requires ongoing dialog to discover areas for working together. Instead of bringing a finished product or preconceived plan, see what can be developed mutually. The AIDS catastrophe affects so many people and organizations that the opportunities for working together are endless.

\* Once this groundwork is done, one still must tell people about their opportunity to help. Reaching the public is a separate challenge. But there are self-starters who can pick up an issue from a friend's email or a newspaper, without needing an organization to provide someone to hold their hand. And we can publicize campaigns by coordinating them with major news stories.

\* We should pay attention to developing actions that fit gracefully into peoples' lives. We need to understand and address their real reluctances to act. Contacting state or federal political representatives, civic or political organizations, corporate offices, etc. should not be a high-anxiety chore.

Perhaps citizen action could become a practice worth doing for its own sake -- designed to guide us through effective styles of everyday living. Imagine a discipline like Tai Chi, only built on interpersonal moves instead of physical ones. (This writer started a Web site to explore the possibility,  
<http://www.communicationpractices.org>.)

The bottom line is that by properly

targeting our action campaigns, and negotiating the right consensus and sign-on in advance, we can involve many more people than before -- without necessarily building a major national grassroots organization, something the AIDS community has not yet been able to do. Better use of the skills we already have could increase public response many times over. We are addressing people who already agree with us on the issues. The critical need now is to provide specific actions that truly work for them.

## **Bush Proposes Near Tripling of U.S. Commitment on Global HIV Epidemic**

by John S. James

In what is widely seen as a groundbreaking advance, President Bush proposed additional U.S. funding of almost \$10,000,000,000 over the next five years for fighting the global HIV epidemic. The president made this unexpectedly major announcement in the State of the Union speech on January 29, 2003. If appropriated by Congress, the money would bring the total spending over five years to about \$15,000,000,000. The measure will have strong bipartisan support, but passage is not assured.

The proposed U.S. initiative is for 14 countries, 12 of them in Africa, that together have about half of the HIV-infected people in the world. Over five years, it aims to prevent 7,000,000 new HIV infections (60% of the number projected for those countries), treat 2,000,000 people with HIV, and care for 10,000,000 HIV-infected individuals and AIDS orphans. (The countries are Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa,

Tanzania, Uganda, and Zambia; for initial ideas on how the program may work within these countries, see the January 29, "Fact Sheet; the President's Emergency Plan for AIDS Relief" at <http://www.whitehouse.gov/news/releases/2003/01/20030129-1.html> -- check later information if available). The program will start in fiscal year 2004 (the U.S. government fiscal year 2004 begins October 1, 2003), with funding expected to begin slowly and ramp up in later years. This proposal is not finished, and much is being worked out now in discussions among the White House, Congress, and global AIDS and health organizations.

The announcement came as a surprise even to members of Congress, and European and other governments -- apparently because President Bush and his administration were weighing many factors and were not sure what HIV program (if any) would be announced until shortly before the speech. It was known that administration officials and AIDS experts had been working quietly for months to develop an initiative to address the global epidemic. We have heard that President Bush was given several proposals, and chose one (the one, incidentally, with the largest total funding). This plan includes a comprehensive prevention program (including abstinence and condoms), and an equal emphasis on prevention and treatment, including antiretrovirals.

This high-profile announcement is already changing the tone of the discussion, with talk in Washington shifting from whether there should be a larger U.S. program to how to make it work. A key issue is getting European and other donor nations to also increase their commitment to fighting an epidemic that could kill a third of the entire population of many countries, and is spreading rapidly today in huge populations in Asia and Eastern Europe. ,

## Some Widespread Criticisms

While the announcement was universally welcomed and the plan is considered credible, there have also been some widespread concerns:

\* Even if Congress acts favorably, this plan will not formally start until October, and then will build slowly as the U.S. negotiates and develops new management and oversight structures in the 14 countries instead of using what is already available. Meanwhile, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, started by United Nations Secretary-General Kofi Annan (and now to be headed by U.S. Secretary of Health and Human Services Tommy Thompson), is running today and has excellent proposals ready to go, delayed only by lack of money. But the president's initiative de-emphasizes the Global Fund, and we have heard that administration officials are lobbying Congress not to provide more money. Either they want to see a track record first, with statistical proof of results like number of infections prevented, or they want to control the geopolitical impact of the funding. In either case the result is more delay. Yet in an epidemic, the best time to act is now.

Activists have, however, noted one advantage of the president's initiative over the Global Fund. The new U.S. program is likely to provide antiretroviral treatment to more people than the Global Fund, which developed earlier when treatment was more controversial. Today it is more widely recognized that treatment must be included to make prevention work, since otherwise people have no incentive to come forward for testing, or to help organize prevention and care programs in their communities.

\* Health and development experts are

concerned that the president's proposal is heavily weighted toward bilateral agreements between the U.S. and each of the 14 countries, instead of multilateral institutions like the Global Fund. Multilateral approaches can better leverage contributions from other donor countries, and coordinate the worldwide fight. Separate donor programs could increase bureaucracy (including multiple application and reporting requirements for the recipient countries) and reduce effectiveness.

Instead of using the Global Fund or other international agencies, the president's initiative calls for oversight by a Special Coordinator for International HIV/AIDS Assistance, to be confirmed by the Senate with a rank of ambassador, and report directly to the Secretary of State. It includes some support for the Global Fund, but only about ten percent of the total. Development experts hope that this small support for multilateral programs can be increased.

\* The president's initiative proposed \$10,000,000,000 in new money and \$5,000,000,000 being spent already, both over five years. Where will the billion dollars a year in "old" money come from? "Mr. Bush in his State of the Union speech proposed new spending to fight AIDS and HIV in Africa and the Caribbean. But his budget for 2004 would reduce by about the same amount the funding that aides had said would be sought for a separate development-aid initiative for poor nations," ("Budget for Hard Times Offers New Plans but Many Cutbacks, by John D. McKinnon and Greg Hitt, *The Wall Street Journal*, February 4.)

The president's budget request, released February 3, includes major cuts in child health and survival programs, which include routine vaccination, according to the *Boston Globe* ("U.S.